

Palliative care in Colombia

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This paper explores the development of palliative care in Colombia from its beginning with two pioneer initiatives in the 1980s to its current situation. We describe specific factors that influence the country-wide provision of palliative care, such as: palliative care education, the organisation of the national health care system and the availability of opioids, as well as social and political attitudes towards end-of-life care. Two main sources were used to gather the information presented here:

1. *Recorded and transcribed telephone interviews conducted between February and April 2004. Six palliative care pioneers in Colombia were interviewed: three palliative care specialists, two psychologists and a bioethicist.*
2. *A systematic review of the 1970–2004 literature on end-of-life care in Colombia was conducted between September 2003 and May 2004.*

HISTORICAL BACKGROUND

Palliative care emerged in Colombia during the 1980s as a result of the importance given by a handful of enthusiastic health professionals to the need for skilled end-of-life care. After having been in contact with dying patients, they became aware of the problem of unrelieved suffering and pain at the end of life, and the lack of available expertise and information in the country. Two leading palliative care initiatives appeared subsequently: (i) the Omega foundation, in Bogotá; and (ii) the palliative care programme in 'La Vega', in Cali.

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The Omega foundation

A group of physicians, nurses, psychologists and social workers led by the psychologist Ms Isa Fonnegra de Jaramillo formed the Omega foundation in 1987 (1). It was privately funded and it constituted a non-profit making initiative undertaken in Bogotá. Local and regional support of professionals as well as international links with experienced practitioners working at existing palliative care institutions in the US and in Europe were crucial to fostering the creation of the foundation, by providing clinical and managerial expertise as well as philosophical support (2). Omega constituted the earliest and one of the leading palliative care organisations in Colombia.

The palliative care service was created with the primary objective of providing multidisciplinary and holistic palliative care to patients dying of cancer or AIDS at home and at local hospitals as well as bereavement support for their relatives (3). Its ultimate aim was to encourage the development of palliative care as a medical discipline, country-wide. In 1989, the Omega foundation pursued the idea of creating the first hospice in Colombia that would provide in-patient care as well as out-patient and home care and a day-care centre. However, the building intended to host the hospice was seriously vandalised and finally burnt down by members of the local community who feared the proximity of dying patients some of whom were understood to be dying of AIDS. The project was unable to get underway. The foundation, therefore, continued as a home palliative care team.

Most health professionals working at the Omega foundation had expertise in counselling and bereavement support as they had previously cared for grieving people who had suffered violent losses, mainly in wars and natural catastrophes. They understood the importance of multidisciplinary team work in looking after dying patients and recognised the lack of awareness within Colombian society on issues relating to end-of-life care.

The foundation promoted palliative care education by organising the earliest multidisciplinary courses in the country directed at health professionals and encouraged public discussion on dying and death, human suffering, pain and dignity, and patients' autonomy at the end of life. There were television and radio broadcasts on the subject as well as regular features in the press (4). The foundation also sponsored the first Colombian palliative care congress that took place in Bogotá in 1987 (5).

During the decade 1990–2000, Omega was the leading organisation responsible for expanding the notion of palliative care to other health institutions in Bogotá as well as to other cities in the country. However, at the beginning of 2004, the palliative care service was closed down due to financial constraints. Its team has continued to provide support to bereaved people.

The palliative care programme at the Fundación Casa de Recuperación Nuestra Señora de los Remedios La Vega

La Vega was a hospice created by a group of nuns with private financial aid in 1962 (6). It was initially created to look after tuberculosis patients, but 10 years later due to an increasing demand care was also offered to cancer patients.

Cancer patients who came to Cali from distant places to the local hospitals spent a few days there while waiting for their medical appointments, and dying patients were admitted to be looked after until death. There was no structured palliative care programme. Patients were offered shelter, food, a bed and some sort of respite care; it was a humanitarian initiative (7). Some nuns had nursing skills and medical advice was available if needed (8).

In 1989, Ms Liliana de Lima, a psychologist, and Dr Pedro Bejarano, a physician, both interested in palliative care and aware of the need for a more structured approach to end-of-life care presented a project to the sponsors of the initiative in La Vega. They brought forward the idea of developing a comprehensive palliative care programme to make the most of the facilities already available in the hospice (9). By 1996, the palliative care programme in La Vega comprised 52 beds for in-patient care, a day-care centre and an out-patient clinic. Although it only cared for cancer patients, around 3300 patients were admitted into the programme each year (10). Besides its clinical commitments, the programme in La Vega actively promoted the recognition of palliative care within the community by means of disseminating information and encouraging the involvement of local people in the programme's activities. Medical students as well as interested health professionals had the opportunity to acquire knowledge and skills in palliative care. In 1992, it hosted the second meeting for Latin American experts on pain medicine and palliative care, nurturing the development of palliative care locally and regionally.

In 1997, Ms Liliana de Lima left the programme and several members of staff resigned afterwards. As a result, the palliative care service in La Vega was later closed down.

The Omega foundation and the palliative care programme in La Vega represented the most comprehensive and thorough palliative care initiative in the country. Later endeavours developed mostly through hospital palliative care teams as part of the pain service.

CURRENT AVAILABILITY OF PALLIATIVE CARE SERVICES

During the 1990s, subsequent palliative care initiatives developed in major hospitals of the main cities led by anaesthesiologists initially interested in chronic, cancer and AIDS-related pain and who later moved into palliative care.

In Medellín, a city of 1.9 million inhabitants, palliative care is provided at the San Vicente de Paul university hospital at its service for the relief of pain and palliative care (11). This palliative care unit started as a pain clinic in 1981. Its leading anaesthesiologist progressively turned it into a palliative care programme which has focused on caring for terminally ill cancer patients. It functions as part of the oncology service providing pain control and palliative care to adults and children through a specialised out-patient clinic. Its links with the School of Medicine at the University of Antioquia have made possible the availability of undergraduate and postgraduate education on pain control and palliative care for medical students and for health professionals in the region. A specialised bulletin on pain relief and palliative care is published regularly to promote continued medical education on these subjects.

In Cali, a city of 2.2 million inhabitants (12), three services have developed within the public service as follows (13):

1. *The clinic for the relief of pain at the del Valle University Hospital. This service emerged during the late 1980s as a result of a training project designed for students of psychology to address the psychological dimensions of chronic pain care. An increasing demand from cancer services for support in dealing with their terminally ill patients encouraged the development of a palliative care facility. Since 1993, it has been led by an anaesthesiologist. The palliative care service offers home care as well as out-patient and in-patient care to terminally ill patients. Teaching activities for the clinical and psychological management of chronic and cancer pain are offered to students of geriatrics, psychology and social work.*
2. *The clinic for the relief of pain and palliative care of the Social Security Institute. This service emerged in 1991 and has strong links with the Libre de Cali University. The ultimate aim of this initiative is to provide holistic care for patients suffering from chronic and cancer pain and to support their families throughout the illness and during the bereavement process. The pain and palliative care team offers training opportunities to medical students and to anaesthesiologists. It organises an annual symposium on pain medicine and palliative care.*
3. *The pain medicine section of the Valle del Lili clinic foundation. This was opened in 1994 and operates as part of the anaesthesiology service. A nurse and a*

Table 1. Main characteristics of the palliative care services currently available in Colombia

City	Service name (public/private)	Modality		Service provided			Population cared for		Main pathologies			Training opportunities
		HPCT	HCT	OPC	IPC	HC	Adult	Children	Cancer	Terminal illnesses (other than cancer)	Chronic non-malignant pain	
Bogotá	National Cancer Institute (public)	✓	N/A	✓	✓		✓	N/A	✓ (mainly)	AIDS. Cardio- vascular and neurological chronic conditions may be included	✓	A 6-month training programme is offered to two physicians over the year (one per semester).
	Santa Fe foundation (private)	✓	N/A	✓	✓		✓	N/A	✓	N/A	✓	Nurses are trained by working alongside the team
Cali	del Valle University Hospital (public)	✓	✓	✓	✓	✓	✓	N/A	✓	N/A	✓	Teaching activities on chronic and cancer pain management are offered to students of geriatrics, psychology and social work.
	Social Security Institute (public)	P	N/A	✓	✓		✓	N/A	✓	N/A	✓	Training opportunities on chronic and cancer pain management are offered to medical students and to anaesthesiologists. It organises an annual symposium on pain medicine and palliative care
	Valle del Lili clinic foundation (public)	P	N/A	✓	✓		✓	N/A	✓	N/A	✓	N/A
Medellín	San Vicente de Paul university hospital (public)	✓	N/A	✓	✓		✓	✓	✓	N/A	✓	Under- and postgraduate education on the basis of pain control and palliative care are offered to medical students and to health professionals A specialised bulletin on pain relief and palliative care is published regularly to favour continued medical education on these subjects

HPCT, hospital palliative care team; HCT, home care team; OPC, out-patients care; IPC, in-patients care; HC, home care; BS, bereavement support.



Figure 1. City-by-city distribution of palliative care services in Colombia (ratio of palliative care service /million inhabitants in each city described).

pain specialist offer pain control to outpatients and inpatients suffering from acute, chronic and cancer-related pain.

In 1997, the first hospital palliative care team to be available at a public hospital in Bogotá, the country’s capital city with 6.8 million inhabitants, was created at the National Cancer Institute (14). This palliative care team works alongside the hospital’s pain clinic providing out-patient and in-patient care on a full-time basis. Referrals are received from many distant areas in the country where palliative care is not available (15). It constitutes one of the most recognised palliative care initiatives in Colombia. Because of its location at the main public cancer hospital in the country, palliative care practitioners at this Institute have been able to collaborate with the Colombian Ministry of Health in order to promote more favourable policies on cancer pain control, palliative care and on the availability of opioids country-wide (16,17).

From 2000 onwards, palliative care services have also become available within the private sector. For instance, FUNDALIVIO is a private clinic for the relief of pain and for the provision of palliative care created in Cali, and the Santa Fe foundation has been established in Bogotá (18). The latter functions as part of the foundation’s pain clinic and, together with the palliative care team at the National Cancer Institute, provides training opportunities for health professionals interested in pain control and palliative care (19).

The most relevant characteristics of Colombian palliative care services are summarised in Table 1.

There are no hospices in Colombia and, following the decline of the Omega foundation, there are no formally

recognised home palliative care teams. With the exception of the service available at del Valle University Hospital in Cali, home care is provided only in very limited circumstances, usually by health professionals working at smaller hospitals and supervised by the main hospital’s palliative care team (20). There are no hospital beds exclusively allocated to palliative care and most palliative care practitioners act as specialist advisers or consultants in the management of palliative care patients admitted to general hospital wards. There are no formally established day-care centres and bereavement support is usually provided by one of the members of the palliative care team.

Palliative care is mostly available in three main cities – Bogotá, Cali and Medellín – and it seems to be non-existent in other locations (Fig. 1). Despite its growth since 1990, the palliative care service per million inhabitant ratio shows that greater investments in the discipline are needed if services are to reach the people who might benefit from it.

PALLIATIVE CARE EDUCATION

As shown in Table 1, formal palliative care training is scarce in Colombia. Most current practitioners have acquired their knowledge and skills abroad. Well-established centres in Europe, the US and Canada have offered the most training opportunities (21).

Locally, training programmes are only available in Bogotá and these are usually undertaken by anaesthesiologists, oncologists, clinicians and family care physicians. There is no formal training available for nurses and most of them gain their experience by working alongside a palliative care team (22). Palliative care educational meetings during pain conferences constitute one of the most important opportunities for sharing and updating specialised information. Although medical students at the Hawariana University in Bogotá have the chance to visit the palliative care service at the National Cancer Institute, subjects relating to dying, death or palliative care have not been formally included in the undergraduate curriculum of either medical or nursing students (23).

PALLIATIVE CARE WITHIN THE NATIONAL HEALTH CARE SYSTEM

The Colombian health care system has gone through a profound transformation since 1993 as a result of a series of governmental measures that aimed to make medical care accessible to the entire population. Before that year, Colombian people paid for medical attention and only those who could afford it received decent care. Adequate pain control for incurably ill patients was only available in private clinics (24).

In 1993, ‘Law 100’ (Ley 100) was enacted to make access to health services equal for the whole population

independently of an individual's financial and/or social circumstances, with a target date of 2000. The mechanism for generating, distributing and managing health resources was privatised, decentralised and passed on to non-governmental organisations which would operate under the supervision of the government. As a result, medical services and programmes were re-organised. Access to adequate pain control was considered a patient's right for the first time and the government committed itself to procuring the necessary funds, facilities and training programmes to ensure improvements in pain control (25). Palliative care, however, remained undefined and the consequences for its provision have been diverse.

On the one hand, those institutions, such as the Omega foundation, that charged a fee to patients who could afford it to sustain the palliative care service went bankrupt as most patients and families refused to pay for being looked after when medical care became freely available in main hospitals (26). On the other hand, palliative care continued to be undervalued and poorly recognised by national health authorities and most public and private local institutions (27). The provision of professional care to the terminally ill has not been given relevance in new health policies and thus, there are neither the facilities nor a sufficient number of adequately trained specialists to provide holistic care to this group of patients. In most institutions where a palliative care programme exists, information available to patients and carers and to other health professionals about its philosophy and possible benefits is usually insufficient (28).

AVAILABILITY OF OPIOIDS

It is widely accepted that a better trend on morphine consumption usually correlates well with actions undertaken towards improving pain control (29). According to estimates for the 2001–2005 period made by the International Narcotics Control Board (INCB) (Statistics for 1998), Colombia would consume an average of 72 Defined Daily Doses (DDD) of morphine per day and per million inhabitants during the 5-year period considered (30,31). This represents a consumption of morphine almost three times higher than the estimates of 25 DDD for the 1983–1987 period. The more recent figure places Colombia in third place in morphine consumption in South America after Argentina and Chile which are the first and second highest consumers of opioids for medical purposes in the region.

Prompted by the World Health Organization (WHO) programme on cancer pain relief, several initiatives were undertaken in Colombia to address the problem of poor cancer pain management during the 1990s. In 1989, the Colombian Association of Anaesthesiology favoured the creation of a Pain Committee that aimed to promote education and training in cancer pain relief amongst health professionals in the country. The strengthening of the earliest

palliative care programmes as well as the creation of the Colombian Association for the Study of Pain (the Colombian Chapter of the International Association for the Study of Pain [IASP]) served to call attention to the need for effective national health policies to improve cancer pain management and to promote regional, national and international educational events (32,33).

However, Colombian consumption of 0.74 mg per capita of morphine remains very much below the global average of 5.54 mg per capita (34,35). The reasons for this relatively low medical use of opioids probably stem from Colombia's history in the illegal trade of narcotics, from professional and public attitudes towards the use of these drugs and from deficient governmental mechanisms for ensuring the adequate availability of opioids while avoiding diversion.

Over the last four decades, Colombia has been a world leader in the production, manufacture and distribution of illegal cocaine as well as heroin and other narcotics (36). Although restrictive legislation on opioids may have constituted one of the main barriers to the adequate availability of opioids for medical use in the country, many other factors, such as bureaucracy, inefficient governmental systems for controlling the production, distribution and sale of these drugs, as well as health professionals' and society's misunderstanding of the use of opioids for symptom control in end-of-life care and fear of addiction have been described in the literature and in interviews, as shown in Table 2 (37–42).

END-OF-LIFE CARE IN THE COLOMBIAN SOCIAL CONTEXT

The illegal drugs' market together with high levels of poverty and social vulnerability have also contributed to rising levels of violence through street wars, kidnappings and homicides which constitute one of the principal causes of death amongst the Colombian population (43). These factors have shaped the country's epidemiology and demography over the last decades (44).

In this context, addressing dying and death matters with colleagues, students, patients and families or with the public can be hugely challenging for most palliative care practitioners as people may react ambivalently to the idea of a terminal illness. While ignorance and stigma may lead some people to respond aggressively to end-of-life care initiatives, as experienced by the Omega foundation in 1989, other sectors may show an interest in dying and death matters. For instance, the first edition of the book *De cara a la muerte* (Facing death) launched in 1999 was completely sold out in a matter of days (45).

More recently, courses on dying and death offered to health professionals, students and the public at the Colombian Institute of Bioethics Studies have been highly

Table 2. Barriers to opioids availability, their consequences and impact on end-of-life care in Colombia

Barrier	Consequence	Impact
Governments, concerned about controlling diversity, regularly change health authorities. Each new authority imposes its own criteria in the control of opioids	<ul style="list-style-type: none"> • Unstable policies • The nation-wide supply of opioids may not constitute a priority for the health authority in charge 	<ul style="list-style-type: none"> • Many health professionals are unaware of the legal requirements for prescribing opioids • Delays in the manufacture and distribution of basic opioids, such as morphine and codeine • The dialogue between palliative care providers, purchasers and health authorities can often be unproductive
Bureaucracy	<ul style="list-style-type: none"> • The narcotics control office usually phones the physician who has prescribed high doses of a strong opioid to verify the prescription 	<ul style="list-style-type: none"> • Many health professionals become concerned about being overseen by health authorities
Restrictive prescription system	<ul style="list-style-type: none"> • Only 10-days' supplies of opioids are allowed to be prescribed to each patient in each consultation 	<ul style="list-style-type: none"> • Patients, or their families, need to come for a new prescription each week. As a consequence, there is a waste of doctors' time and of patients' time, money (travel expenses) and physical energy (specially for those living far away from main cities)
Deficient control systems	<ul style="list-style-type: none"> • Frequent shortage of the legally required prescription form • Commercial morphine is insufficiently stored • Pharmacies overcharge their opioid products 	<ul style="list-style-type: none"> • On several occasions, strong opioids are prescribed in ordinary forms • Morphine becomes unavailable at the pharmacy for many patients who need it • Most opioids are unaffordable to most patients
Deficient distribution systems	<ul style="list-style-type: none"> • Very few places are authorised to sell opioids (<i>e.g.</i> in Bogotá, only four pharmacies can dispense strong opioids) • In many smaller cities, strong opioids are not dispensed and they have to be requested to authorised suppliers in Bogotá • There is frequent shortage of essential opioids such as morphine, methadone or hydromorphone in inner cities, such as Cali 	<ul style="list-style-type: none"> • The initiation of treatments is unnecessarily delayed • The tailoring of treatments and their continuity are seriously jeopardised
Lack of diversity in formulations	<ul style="list-style-type: none"> • Only oral and parenteral formulations of morphine are freely available; methadone can only be used in the context of addiction control programmes. Its use to relieve pain may require further explanations to the regulatory authority 	<ul style="list-style-type: none"> • Patients have to pay for most alternative opioids to morphine, such as oxycodone or fentanyl • There is high risk of treatment discontinuation (costs are unaffordable for most patients)
Health professionals' lack of knowledge and skills to prescribe opioids	<ul style="list-style-type: none"> • Concerns about easing the patient's death due to opioids overdose and respiratory depression • Fear of addiction 	
Health professionals' misconceptions on the opioids	<ul style="list-style-type: none"> • The use of opioids is frequently associated with an illicit act 	<ul style="list-style-type: none"> • Prescribed treatments are not given on a regular basis • Very few doctors are willing to use opioids even during the use of last 48 h of life • Avoidable suffering is perceived in many dying patients
Society's misunderstandings on the role of opioids in end-of-life care	<ul style="list-style-type: none"> • Morphine is usually seen as a 'last resort' and reserved for the very last moment of the patient's existence • Fear of addiction 	

successful in terms of turnout and subsequent feedback (46). But, in the opinion of most palliative care activists, terminal illness, dying, and death remain taboo in Colombian society.

COLOMBIA AND THE PRACTICE OF EUTHANASIA

In 1997, Colombia became the first Latin American country to consider the legalisation of euthanasia. In that year, the Colombian Constitutional Court passed on a bill to decriminalise the practice of euthanasia to the National Parliament. Euthanasia had to be requested by a terminally ill patient in unbearable pain and conducted by a qualified physician to be officially permissible (47). The Colombian Parliament did not approve this motion, but neither did it rule it out. As a consequence, although the legal technicalities of its practice have not been fully established and implemented, a physician taken to court having performed euthanasia can be exonerated of his or her responsibility based on this constitutional statement (48). Colombian society adopted a variety of positions in relation to this initiative. While the more conservative sectors as well as the Catholic Church strongly opposed it, public surveys conducted by the local media showed that a certain proportion of lay people perceived euthanasia as a more valid alternative than medical futility for incurably ill patients (49). Other lay sectors and organisations, such as the 'Pro derecho a morir con dignidad' (For the right to die with dignity) foundation, supported euthanasia as an option at the end of life, arguing the principle of respect for autonomy (50). A survey carried out by the Colombian Institute of Bioethics Studies amongst practising physicians who hold clinical and teaching commitments revealed that a significant percentage of the people who replied (about 40%) accepted euthanasia as an option at the end of life and stated that they would themselves consider requesting euthanasia if incurably ill (51).

Those palliative care practitioners who were interviewed also held different views on euthanasia. Some strongly disagreed with it and preferred to define themselves as well as their palliative care activities in clear opposition to its practice (52). Others considered that euthanasia might constitute an option at the end of life in very particular and well-defined circumstances in which suffering and distress cannot be ameliorated, despite providing the best possible palliative care (53–55). Palliative care was unanimously recognised as the best possible approach for end-of-life care. To be effective, it should be accessible, holistic and provided by multidisciplinary teams of well-trained professionals and with appropriate and sufficient resources. Conceived as such, palliative care may imply costs that the Colombian health system has not been prepared to meet.

CONCLUSIONS

Palliative care in Colombia has grown slowly. Only the two earliest and now defunct initiatives, the Omega foundation and the palliative care programme in La Viga, implemented a more holistic approach in the care of the terminally ill. Probably due to the professional background of their leaders and the resources available, subsequent endeavours have emerged that are linked to pain clinics and focused on the control of symptoms of cancer patients, while less attention has been given to the care of the social, psychological and spiritual dimensions of the dying.

Future palliative care in Colombia faces several challenges:

- ^a to promote the development of specialised palliative care services, including palliative home care, based upon the community's needs*
- *to encourage the development of strategies to foster palliative care education and research*
- *to ensure a holistic approach to care for palliative care patients looking at the control of physical symptoms as well as providing psychological, social and spiritual support*
- *to help health professionals and community members to deal with the control of symptoms of a terminal illness as well as with the effects of stigma on the dying*
- *to inform health professionals and the public about the philosophy of palliative care*
- *to encourage discussion on end-of-life matters amongst professionals and the public.*

Strong arguments exist to support palliative care as the best and most efficient approach to end-of-life care. In a Catholic country in which people seem to have become increasingly concerned about medical futility, increasing social and governmental awareness of the need for improvements in end-of-life care depends very much upon strengthening public and professional education on the subject; generating research-based information on needs and resources; and on collaboration amongst experienced palliative care practitioners, pharmacists, health authorities and health educators in setting standards and plans of action. International support by means of expert advice may be of great value to these commitments.

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45. Ms Isa Fonnegra de Jaramillo, IOELC interview, 29 March 2004, length of interview: 67 min.
46. Dr Sanchez Torres, IOELC interview, 30 April 2004, length of interview: 34 min.
47. Dr Sanchez Torres, IOELC interview, 30 April 2004, length of interview: 34 min.
48. Dr Sanchez Torres, IOELC interview, 30 April 2004, length of interview: 34 min.
49. Dr Sanchez Torres, IOELC interview, 30 April 2004, length of interview: 34 min.
50. For further information on the 'Pro derecho a morir con dignidad' (For the right to die with dignity) foundation's aims and activities visit its web site at <http://www.dmd.org.co/index.html> (Spanish only).
51. Dr Sanchez Torres, IOELC interview, 30 April 2004, length of interview: 34 min.
52. Dr Helena Restrepo, IOELC interview, 3 April 2004, length of interview: 64 min.
53. Dr Sanchez Torres, IOELC interview, 30 April 2004, length of interview: 34 min.
54. Ms Isa Fonnegra de Jaramillo, IOELC interview, 29 March 2004, length of interview: 67 min.
55. Dr René Rodríguez, IOELC interview, 26 April 2004, length of interview: 37 min.